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TITLE: A Longitudinal Study of Emotional Distress and the Use of Complementary and Alternative Medicine in Women with Breast Cancer

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Introduction

The purpose of this study is to examine the extent to which levels of depression and anxiety and coping at three-five months post-diagnosis are related to complementary and alternative medicine (CAM) use at initial assessment and follow-up at 9 and 15 months. This study will also identify the types of CAM sought after by women with higher levels of anxiety and depression. Additional aims of the study are to provide pilot data for further research in developing interventions (such as mood regulation skills, coping skills training or treatment information) to meet the emotional needs and healthcare expectations of breast cancer patients. This study is funded as a predoctoral training grant. The research study serves as Ms. Shumay's doctoral dissertation.

Body

During this middle phase of the project, the primary function for the research team was to recruit participants and collect data. For one year, we have been recruiting through four main efforts: physicians directly offering our recruitment brochure to eligible women; our brochure being sent by mail to women in the American Cancer Society Reach to Recovery program; and our brochure being sent to women who are patients of a major breast cancer surgeon in Hawaii.

In addition to these efforts, we have also attempted to boost recruitment via the following activities: we approached 10 surgeons on Oahu with high volume breast cancer patient-loads to encourage them to distribute the brochure to their patients, talked about the study on radio and television, attended cancer support group meetings, created a website (www.crch.org/bccam), spoke at an American Cancer Society event, staffed Cancer Research Center booths at community and professional events, spoke to area physicians at a clinical trials update meeting, networked at a breast cancer conference, brainstormed with Kaiser-Permanente's oncology coordinator, placed our materials at a dozen clinic and physician's waiting rooms and met with the CEO of the Hawaii-Pacific American Cancer Society.

These efforts have yielded 51 enrolled participants or less than one-half of the targeted sample size (125). There are approximately 1,000 women diagnosed with *in situ* or invasive breast cancer in Hawaii each year according to the Hawaii Tumor Registry (Hernandez, 2003). About 800 of these cases are those in which this is the first diagnosis of any cancer and are not staged as distant metastasis. Approximately half of these are diagnosed in Oahu's major hospitals making them available to the physicians through whom we are recruiting during a one year period. That brings us to about 400 women available to us for recruitment. To date we have 51 women enrolled in the study or just over 10% of the available patients. From our analysis of recruiting efforts, it appears that the most successful route to recruiting was the effort to send brochures directly to women with an introductory letter from their physician. To boost our number to reach our targeted sample size, we will focus future efforts in this direction by expanding the number of physicians that have sent out personal letters from one to as many as six. We are also investigating expanding the study to other regions outside of Hawaii where the population is larger.

In addition to recruitment efforts, the research team has been collecting data. Approximately 67 women responded to our brochures by either telephone or mailed response card. We sent these women our initial survey packet (T1) which includes a cover letter, consent form, 12-page questionnaire, study pen, and return envelope. Of these 51 returned the questionnaire (a 76% response rate). Nonresponders were sent reminder cards. Of the 51 women who returned T1, 29 reached the number of months since diagnosis (9) to make them eligible for T2 and were sent the T2 packet. Twenty-two of these participants returned the T2 packet (24% attrition rate). Nonresponders were sent reminder cards. To date, no participants have been sent T3 packets.

We continue to prepare materials for the study, reproducing cover letters and consent forms for mail surveys and producing hundreds of recruitment brochures with response cards to be distributed. We also produced questionnaire sets and mailing packets. We redesigned the questionnaire sets for T1 and T2 distribution. We purchased supplies including envelopes, pens, labels, paper, cardstock and other miscellaneous supplies. We renewed IRB requirements with the University of Hawaii and Kaiser-Permanente. Over the year, we have developed a research team of undergraduate volunteers who were interested in learning about cancer research. A total of six undergraduates have spent time as research assistants, preparing materials for the study, doing library research, meeting to discuss topics in psychooncology, scanning questionnaires and managing the study database.

To date we have scanned the questionnaires of 47 of the participants and can report on preliminary demographic and treatment information for the sample. The mean age of the participants is 56.9 (SD = 10.8; range 34-85 years). The majority of the sample are of nonwhite ethnicity. Individuals of Japanese ancestry make up 25.5 percent, Caucasian 29.8 percent, Native Hawaiian 27.7 percent, Filipina 6.4 percent, other Asian (Chinese or Korean) 8.5 percent and other (2.1%). Educational levels of participants are as follows: 19.2% had a highschool diploma or equivalent; 42.5% attended college; and 38.3% attended graduate or professional school. Roughly 17% had annual family incomes of \$25,000 or less, 14.9% had incomes of \$25,000-\$50,000, 40.4% had incomes of \$50,000-\$100,000, 19.2% had incomes of greater than \$100,000. About 70% of the sample were married or co-habiting, and 29.8% were single, divorced or widowed. Nearly 28% of the sample reported having been treated for emotional difficulties before being diagnosed with breast cancer, while 8.5% reported having been treated for emotional difficulties since diagnosis. Regarding cancer treatment choices, 72.3% of the women had a lumpectomy with or without radiation and 46.8% had a mastectomy, either initially or after lumpectomy. About 34% also had chemotherapy, 19% also had hormonal therapy and 14.9% opted for breast reconstruction. During the month preceding the assessment, 77% received some cancer treatment, while 23% had not received any treatment. Some 23% of women stated that they had chosen not to have some treatment that the doctor had recommended. Of the 90% of women who knew their stage, over 50% reported having stage 1, 23% reported stage 2 and 13% reported stage 3 or higher.

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Key Research Accomplishments

- Recruited 51 participants and collected data
- Developed study database
- Conducted preliminary descriptive analysis on sample
- IRB approval renewed
- Study materials prepared
- Developed relationships with key breast cancer surgeons in community
- Attended professional conferences and meetings promoting the study
- Attended an international cancer conference and presented a paper
- Included undergraduate students on research team

Reportable Outcomes

- Received a Best Student Poster award at international cancer conference
- Evaluating as “outstanding” by program faculty for work on project
- Trained six undergraduates in the fundamentals of research
- Continue to make satisfactory project on dissertation toward defense in May 2004

Conclusions

In conclusion, during this middle phase of the project, the primary function for the research team was to recruit participants and collect data. Fifty-one participants have completed the first questionnaire of the study and 22 have completed the second questionnaire, yielding preliminary descriptive results about the sample. The award has supported a quality training experience for Ms. Shumay and has supported her to continue to make satisfactory progress on her dissertation with targeted defense date in May 2004. In addition to supporting the quality training of a future breast cancer researcher, this project has the potential to further cancer research in a number of ways. This study should allow us to better understand the relationship between emotional distress and treatment decisionmaking in breast cancer, as well as to help underscore the importance of identifying and treating anxiety and depression after diagnosis. The results may serve to form the basis for further research in determining the appeal of CAM for emotionally distressed breast cancer patients with the goal of designing relevant interventions.

References

Hernandez, B. Y. (2003). Highlights of recent cancer incidence data in Hawaii. *Hawaii Medical Journal*, 62, (17-18).

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Appendices

Date

Ms. «First» «Last»
«Address»
«City», HI «Zip»

Hello!

I support cancer research because I believe research is important to benefit current and future breast cancer patients. Right now, researchers at the Cancer Research Center at the University of Hawaii are conducting a written survey of women who have recently been diagnosed with breast cancer. This survey will explore how women cope emotionally with breast cancer diagnosis and how they make decisions regarding treatment including the decision to use or not to use complementary medicine. Hopefully, the information the study yields will aid in helping to improve future care for women with breast cancer.

Enclosed is a pamphlet describing the study. If you are interested or have any questions regarding the study, please call the study coordinator, **Dianne Shumay at (808) 564-5840** or feel free to call our office with any concerns you may have. Whether you decide to participate or not is up to you – your decision will not affect the medical treatment you receive.

Thanks for helping us help cancer research!

Warmly,

Name

Thank You!

The Cancer Research
Center of the
University of Hawaii

Your Emotions &
Treatment Choices
for Breast Cancer



If you would like to
participate in our
study, just complete
the response form
contained in this bro-
chure. Or call us at
564-5840!

BCCAM
A new study for
women with breast
cancer from the
Cancer Research
Center

Feb. 908-564-5840

www.crch.hawaii.edu/bccam

The Cancer Research Center of the
University of Hawaii

Cancer Research Center of Hawai'i
Clinical Sciences Program
1236 Lauhala Street Suite 406
Phone: 808-564-5840
Fax: 808-586-2984
Email: bccam@crch.hawaii.edu



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Breast Cancer, Emotional Wellbeing and Complementary and Alternative Medicine Study

Second Questionnaire

DIRECTIONS FOR FILLING OUT THIS SURVEY

Thank you for taking part in our study. The questionnaire you fill out will be read by a machine, therefore we ask that you follow these directions:

1. Please use a BLACK pen to mark your answers.
2. Please return all pages of this questionnaire, and keep pages together with the clip provided. Please do NOT staple your pages together.
3. If you make a mistake and mark an answer that you did not mean to mark, simply put a large X through the incorrect mark. Then, proceed to mark your correct answer. We will disregard the mark with an X.

Shade our circles like
this:



*(Please fill in the circles completely, and only
place a large X over a circle that you have
mistakenly filled)*

Not like this:



For best results, please avoid contact with the edge of the boxes. The following will serve as an example:

--	--	--	--	--	--	--	--	--

If you have any questions about or need assistance in filling out this questionnaire, please feel free to call Dianne Shumay, MA at 564-5840 or Dr. Gertraud Maskarinec at 586-3078.

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Health Therapies Questionnaire

Below is a list of therapies that some people use for health reasons. Please indicate which therapies, if any, that you have tried. And for those you have used, indicate how regularly you have used them and your level of satisfaction. *Please see attached page for definitions of health therapies.*

	Have you ever used this?	Do you currently use this?	Did you start using this before (B) or after (A) cancer diagnosis?	If yes, how regularly have you used this therapy? (circle)							If yes, how satisfied are you with this therapy? (circle)						
				Used once	Somewhat regularly	Very regularly	Very dissatisfied	Neutral	Very satisfied	Very dissatisfied	Neutral	Very satisfied	Very dissatisfied	Neutral	Very satisfied		
Chiropractic	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Acupuncture/Acupressure	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Massage therapy or bodywork	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Homeopathic medicine	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Relaxation techniques	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Hypnosis or self-hypnosis	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Yoga	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Religious healing or prayer	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Support group	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Osteopathy	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Traditional Hawaiian healing	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Energy healing (i.e. healing touch, Reiki)	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Meditation	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Guided imagery/visualization	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					
Naturopath	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7					

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	Have you ever used this?	Do you currently use this?	Did you start using this before (B) or after (A) cancer diagnosis?	If yes, how regularly have you used this therapy? (circle)							If yes, how satisfied are you with this therapy? (circle)						
				Used once	Somewhat regularly	Very regularly	Very dissatisfied	Neutral	Very satisfied	Very dissatisfied	Neutral	Very satisfied	Very dissatisfied	Neutral	Very satisfied		
Tai Chi or Qi Gong	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7		
Aromatherapy	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7		
Herbs or botanicals	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7		
Special diet	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7		
Vitamins	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7		
Other supplements	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7		
Exercise	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7		
Other non-medical therapy	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> Y <input type="radio"/> N	<input type="radio"/> B <input type="radio"/> A	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7	1 2 3 4 5 6 7		

Please list herbal/botanical therapies you take currently:

Please list vitamins, minerals and other supplements you take currently:

Please describe any special diets that you are currently on:

Please list any other non-medical or alternative therapy you have used that is not included on the list above:

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MAC Scale

A number of statements are given below which describe people's reactions to having cancer. Please fill in the circle underneath the statement, indicating how far it applies to you at present. For example, if the statement definitely does not apply to you, then you should fill in the circle in the first column.

	Definitely does <u>not</u> apply to me	Does <u>not</u> apply to me	Applies to me	Definitely applies to me
I have been doing things that I believe will improve my health (e.g. changed my diet)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I can't do anything to cheer myself up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that problems with my health prevent me from planning ahead	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe that my positive attitude will benefit my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't dwell on my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I firmly believe that I will get better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that nothing I can do will make a difference	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've left it all to my doctors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that life is hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been doing things that I believe will improve my health (e.g. exercised)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Since my cancer diagnosis I now realize how precious life is and I'm making the most of it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've put myself in the hands of God	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have plans for the future (e.g. holiday, jobs, housing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about the cancer returning or getting worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've had a good life, what's left is a bonus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think my state of mind can make a lot of difference to my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that there is nothing I can do to help myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to carry on my life as I've always done	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would like to make contact with others in the same boat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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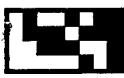
<input type="text"/>	<input type="text"/>	<input type="text"/>
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	Definitely does <u>not</u> apply to me	Does <u>not</u> apply to me	Applies to me	Definitely applies to me
I am determined to put it all behind me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty in believing that this happened to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I suffer great anxiety about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am not very hopeful about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At the moment I take one day at a time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like giving up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to keep a sense of humor about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other people worry about me more than I do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think of other people who are worse off	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am trying to get as much information as I can about cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I can't control what is happening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to have a very positive attitude	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I keep quite busy, so I don't have time to think about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoid finding out more about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I see my illness as a challenge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel fatalistic about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel completely at a loss about what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel very angry about what has happened to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't really believe I had cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I count my blessings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to fight the illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Self-Evaluation Questionnaire - Form Y1 (STAI)

A number of statements which people have used to describe themselves are given below. Read each statement and then fill in the appropriate bubble under the statement to indicate how you feel *right now*, that is *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately So	Very Much So
I feel calm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel secure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am tense	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel strained	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel at ease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel upset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am presently worrying over possible misfortunes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel satisfied	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel frightened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel comfortable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel self-confident	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am jittery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel indecisive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am relaxed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel content	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confused	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel steady	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel pleasant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Self-Evaluation Questionnaire - Form Y2 (STAD)

A number of statements which people have used to describe themselves are given below. Read each statement and then fill in appropriate bubble under the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	Not at all	Somewhat	Moderately So	Very Much So
I feel pleasant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel nervous and restless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel satisfied with myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wish I could be as happy as others seem to be	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like a failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel rested	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am "calm, cool, and collected"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that difficulties are piling up so that I cannot overcome them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry too much over something that really doesn't matter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am happy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have disturbing thoughts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I lack self-confidence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel secure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I make decisions easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel inadequate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am content	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some unimportant thought runs through my mind and bothers me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I take disappointments so keenly that I can't put them out of my mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am a steady person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get in a state of tension or turmoil as I think over my recent concerns and interests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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CES-D

Fill in the circle for each statement which best describes how often you felt or behaved this way - DURING THE PAST WEEK.

	Rarely or None of the Time (Less than 1 day)	Some or Little of the Time (1-2 days)	Occasionally or a Moderate Amount of the Time (3-4 Days)	Most or all of the Time (5-7 days)
I was bothered by things that usually don't bother me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not feel like eating: my appetite was poor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I could not shake off the blues even with help from my family or friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was just as good as other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble keeping my mind on what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that everything I did was an effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt hopeful about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought my life had been a failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt fearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My sleep was restless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was happy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I talked less than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People were unfriendly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I enjoyed life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had crying spells	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that people disliked me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I could not get "going"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Impact of Event Scale (IES)

Below is a list of comments made by people after being diagnosed with cancer. For each item, fill in the number which indicates how frequently these comments are true for you *over the past week*. If they are not occurring, choose "Not at all." While answering the items, think about the experience of being diagnosed with cancer as the event to which the items refer.

	Not at all	Rarely	Sometimes	Often
I think about it when I don't mean to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoid letting myself get upset when I think about it or am reminded of it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to remove it from my memory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have trouble falling asleep or staying asleep, because of pictures or thoughts that come into my mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have waves of strong feelings about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have dreams about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel as if it hasn't happened or isn't real	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try not to talk about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pictures about it pop into my mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I stay away from reminders of it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other things keep making me think about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am aware that I have a lot of feelings about it, but I don't want to deal with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try not to think about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any reminder brings back feelings about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My feelings about it are kind of numb	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Background and Treatment History Questionnaire

1. Today's date

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month / date / year

2. Date of Diagnosis

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month / date / year

3. Which treatments have you received for breast cancer? (Select all that apply)

- Mastectomy
- Mastectomy with sampling of the lymph nodes
- Mastectomy and reconstruction at the same time
- Lumpectomy (partial mastectomy) with sampling of lymph nodes under arm
- Lumpectomy (partial mastectomy) without sampling of lymph nodes under arm
- Chemotherapy
- Radiation
- Hormonal therapy (e.g. Tamoxifen)
- Breast reconstruction after initial surgery
- Prophylactic surgery (removal of non-cancerous breast to reduce future breast cancer risk)
- None of these

4. Which treatments for breast cancer are you currently undergoing or have received in the past month? (Select all that apply)

- Surgery
- Chemotherapy
- Radiation
- Hormone therapy (e.g. Tamoxifen)
- Undergoing no treatment at this time

5. What stage was the breast cancer?

Stage 1

Stage 2

Stage 3

Stage 4

Don't know

6. How big was the tumor? (Describe below)

7. Was the tumor *in situ*?

Yes

No

Don't know

8. Was the cancer found in your lymph nodes?

Yes

No

Don't know

9. Was the cancer metastasized?

(i.e. spread to other parts of the body)

Yes

No

Don't know

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10. Are there any medical treatments that your doctor recommended you receive for breast cancer that you chose not to take?

○ Yes

10

11. If YES to question 10, which treatments that your doctor recommended did you choose not to undergo?
(Select all that apply)

- Mastectomy
- Lumpectomy
- Sampling of the lymph nodes
- Chemotherapy
- Radiation
- Hormonal therapy (e.g. Tamoxifen)
- Prophylactic surgery
(removal of non-cancerous breast to
reduce future breast cancer risk)

If you chose not to undergo any treatments, please give reasons below:

12. Have you ever been treated for the following? (Check all that apply)

a) Depression

- Yes, before diagnosis with cancer
- Yes, after diagnosis with cancer
- No, never been treated

b) Anxiety

- Yes, before diagnosis with cancer
- Yes, after diagnosis with cancer
- No, never been treated

c) Other emotional difficulties

- Yes, before diagnosis with cancer
- Yes, after diagnosis with cancer
- No, never been treated



The BCCAM Study

A Longitudinal Study of Emotional Distress and
Complementary and Alternative Medicine Use
among Women with Breast Cancer

PI: Dianne M. Shumay MA (*tel. 564-5840*)

Faculty Mentor: Gertraud Maskarinec MD PhD

Acknowledgements

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- Elaine Heiby PhD, Committee chair, University of Hawaii Department of Psychology
- Gertraud Maskarinec MD PhD, Mentor, CRCH
- Carolyn Gotay PhD, CRCH
- Anthony Marsella PhD, UH Dept of Psychology
- Karl Minke, PhD, UH Dept of Psychology

BCCAM Study

- Pencil and paper questionnaire survey
- Investigating the relationship between emotional distress, coping and CAM use in breast cancer
- Three data collection points (<5 mos, 9 mos, 15 mos)
- Recruitment goal: 125 women from Hawaii
- Adult women diagnosed with 1st primary *in situ* or invasive breast cancer

Background

- Emotional distress (ED)
 - Depression and anxiety common after diagnosis
- Complementary and alternative medicine (CAM)
 - “Those healthcare and medical practices that are not currently an integral part of conventional medicine.” (NCCAM, 2002)
 - Rates of CAM use **39-72%** among women with breast cancer

CAM & ED: The Connection

Several studies have found a connection between emotional distress, coping and CAM use...

Among Hawaii cancer survivors, poorer emotional functioning on a quality of life scale was significantly related to CAM use (Maskarinec et al., 2000)

Formulating the Study Question

- Why are women with breast cancer using CAM?
- Are women with emotional distress more likely to use CAM?
- What kinds of CAM are women with ED using?
- Are women seeking out CAM because conventional medicine is not addressing ED?

Longitudinal Study

- T1 <5 months post diagnosis
- T2 9 months post diagnosis
- T3 15 months post diagnosis

Participants

- Target: 125 women to start and 100 to finish study
- Criteria
 - Female residents of Hawaii
 - Over 18 years of age
 - <5 months post-diagnosis with breast cancer
 - First primary
 - In situ or invasive cancer, biopsy-confirmed

Human Subjects approval

- CHS, University of Hawaii
- DOD IRB (granting agency)
- Kaiser-Permanente

Procedure

- Interested participants are contacted by telephone or email
- Mailed informed consent and study materials
- Questionnaire packet (approx 45 minutes to complete)
- Procedure repeated at T2 and T3

Implications

This exploratory study will inform further research in determining the appeal of CAM for emotionally distressed breast cancer patients with the goal of designing relevant interventions.

Exploring Women's Experiences with Complementary and Alternative Medicine after Breast Cancer Diagnosis

Dianne M. Shumay MA & Gertraud Maskarinec MD PhD
Cancer Research Center of Hawai'i, University of Hawai'i at Manoa

Background

Complementary and alternative medicine is popular among women with breast cancer, with estimates of CAM use ranging from 39% to 84%.

Younger age, higher educational status and certain psychosocial factors have emerged as predictors of CAM use. Cancer patients in general have stated that they seek out CAM as a source of hope, to increase sense of control, to reduce stress, for spiritual concerns, to strengthen psychological resources for healing and coping with cancer, for symptom control, and to improve quality of life.

We used a qualitative method to explore women's stories of their decision to use CAM after breast cancer and what effects they expected CAM to have on their health.

Themes: Women's Expectations of CAM's Beneficial Effects

Help with Cancer Treatment

"I was already on the program with Dr. X. She told me that her plan for me at that point was to bullet proof my body, so that radiation would only effect what it is supposed to effect and not damage anything else. It really worked. I wasn't even tired. I didn't have any sunburn kind of effect. There was nothing. It was great. It was fun. I got to know all these wonderful people. It was not a problem."

Help Heal and Maintain Health

"The CAM thing is just heal and be cured, which is also a Christian thing, heal, be cured (...) The Christian thought process is to heal and that is a little bit different than the scientific thing in the sense of lets get rid of this growth problem."

"I think they keep me healthy somehow and keep me going. I don't feel tired."

Help Improve Quality of Life

"I think CAM goes a little beyond that, I think CAM therapies would be more concerned with quality of life, not just life. I'm not sure the medical people would agree with me, but that's just a feeling that I have."

Themes: Process of Positive Self-Transformation

"It's just loving life. If I would have named this carpet it would say I love life, enjoy life and all it has to offer (...) This is not my style or art at all, this changed after I got cancer and I started to live. The goal is to get the person well again, not just well from cancer, but to get the whole person well, give them the tools to become stronger and willing to take care of themselves so they can stay well, not just physically well, but learn from all these experiences from cancer so that you can start your life over again and do it right."

"Life is much more meaningful now. The paradox as I have read in other literature since discovering this illness that getting it was a blessing as a paradox, because it forced me to evaluate my life at that point in time and make a decision, that has been only beneficial."

"CAM is life-changing, you really have to make that commitment to do it."

"The goal is to get the person well again, not just well from cancer, but to get the whole person well, give them the tools to become stronger and willing to take care of themselves so they can stay well, not just physically well, but learn from all these experiences from cancer so that you can start your life over again and do it right."

Conclusions

The women interviewed here expressed a willingness to actively seek information and engage in CAM to complement conventional treatment, help with healing, maintain health, gain control and improve mental as well as physical quality of life.

The emergent themes underscored the seeking of CAM as a psychologically positive endeavor that for many women contributes to a life changing transformation after cancer.

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